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SENATE BILL 5929

State of Washington 58th Legislature 2003 Regular Session

By Senators Franklin and Kline

Read first time 02/20/2003. Referred to Committee on Children & Family Services & Corrections.

- 1 AN ACT Relating to informed consent in the use of genetic
- 2 information; and adding a new chapter to Title 7 RCW.
- 3 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF WASHINGTON:
- NEW SECTION. Sec. 1. (1) Any employer or insurer collecting, using, storing, or disclosing for any purpose a person's genetic information must have the person's informed consent to do so.
 - (2) Informed consent requires:

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- (a) An explanation of the purpose for which the genetic information is being obtained, and what form it will be in for interpretation;
 - (b) Identification of the entity obtaining the genetic information;
- 11 (c) Disclosure of any entity with whom the genetic information may 12 be shared, including disclosure that the genetic information may be 13 shared in the future with an unknown entity;
- 14 (d) A statement of the expected duration that the genetic 15 information may be kept;
- 16 (e) A description of reasonably foreseeable risks or harm 17 associated with providing the genetic information;
- 18 (f) An explanation of how the genetic information will be

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1 maintained and whether the physical sample will be destroyed or stored, 2 including how and where it will be stored;

- (g) A statement describing any reasonably expected benefits or advantages associated with providing the genetic information;
- (h) A statement describing any confidentiality or privacy protections for the genetic information;
- (i) Identification of an individual contact and contact information from whom further information may be obtained or reported relative to the genetic information;
- (j) Provisions explaining whether the genetic information can be expunsed or removed from the entity that obtained it and the method to do it;
- (k) The exclusion of any exculpatory provisions from liability against the entity obtaining the genetic information; and
 - (1) A disclosure that providing genetic information is voluntary.
 - (3) A person's informed consent is not required:
 - (a) In criminal matters if the genetic information is obtained or used during a criminal investigation, trial, appeal, or pursuant to specific common law or statutory authority, or a lawfully issued court order. Once a criminal conviction is final, a report that was not admitted into evidence, identifying a specific person by analysis of genetic information obtained in the course of an investigation, shall be destroyed if the person is found to be uninvolved in the commission of the criminal act or acts;
 - (b) In situations where the person requires emergency medical care as long as the person, or his or her representative in death cases, is informed in a timely manner after the emergency that the genetic information was obtained;
 - (c) In situations where a person's bodily fluids are obtained without consent pursuant to specific statutory requirement mandating testing;
 - (d) In situations where the individual is deceased and the entity requesting the genetic information establishes in a court of law that obtaining individually identifiable genetic information benefits public health, safety, and welfare, and outweighs the harm to the individual's privacy interests, or the person requesting the genetic information is a next of kin requesting the genetic information for purposes of health care or other purpose that outweighs the harm to the individual's

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privacy interests, or the entity requesting the genetic information has been authorized by an institutional review board to use the genetic information pursuant to an approved protocol;

- (e) Pursuant to the provisions of this section, if the entity or person is a health care provider or facility under chapter 70.02 RCW or the federal health insurance portability and accountability act privacy rules who is acting according to the provisions of that chapter or federal law, and who is subject to the provisions of chapter 7.70 RCW and the federal health insurance portability and accountability act privacy rules;
- (f) Pursuant to provisions of this section, if the entity or person obtains an individual's genetic information in a form that does not identify that individual or there is no reasonable basis to believe the information can be used to identify an individual;
- (g) Pursuant to provisions of this section, if the entity or person who obtains genetic information is acting according to the provisions of an institutional review board established under federal law;
- (h) In death investigations for purposes of identifying the decedent;
- (i) In matters of parentage proceedings under chapter 26.26 RCW. Genetic information shall not be released or disclosed for any purpose other than that which is relevant to the parentage proceeding without a court order or informed consent of the individual who furnished the specimen; and
- (j) Where the division of child support has issued an order for genetic testing pursuant to RCW 74.20.360. Genetic information shall not be released or disclosed for any purpose not relevant to the division of child support's order without a court order or the informed consent of the individual who furnished the specimen.
- 30 (4) For the purposes of this section, "genetic information" means 31 information about inherited characteristics which can be derived from 32 a DNA-based or other laboratory test, family history, or medical 33 examination.
- NEW SECTION. Sec. 2. Section 1 of this act constitutes a new 35 chapter in Title 7 RCW.

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